



Acceptability and perceived impact of new pediatric patient navigation program in rural Rwanda

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BACKGROUND

Diagnosing and treating cancer is a complex process, often requiring consultations with multiple medical specialists in multiple settings. Patient navigation (PN) is patient-centered approach to facilitate timely access to health care and create a seamless flow for patients through the care continuum.¹ It is a potential strategy to improve treatment outcomes by improving care coordination, eliminating barriers to accessing care, and reducing treatment delays and interruptions.

In the US, PN has become standard of care and has demonstrated effectiveness in increasing timeliness of cancer diagnosis and treatment initiation and decreasing treatment interruption and default rates.²⁻⁴ However, PN strategies have not been widely studied in low-income countries or among pediatric cancer patients.

We piloted a PN program for pediatric patients with nephroblastoma at Butaro Cancer Center of Excellence (BCCOE) in rural Rwanda. Here, we report preliminary acceptability and perceived impact among patient caregivers and healthcare providers after six months of implementation.

METHODS

From 1 March 2020, patients newly diagnosed with nephroblastoma at BCCOE were prospectively enrolled in the PN program. A trained nurse navigator conducted in-depth education for caregivers prior to treatment, using an illustrated booklet (Figure 1); coordinated all medical appointments and referrals between healthcare facilities; reminded caregivers of upcoming appointments; and proactively identified and addressed barriers to care.

On the last day of their child's curative treatment, caregivers were invited to participate in a survey about their experience with and perspective of PN. Half of the caregivers were also invited to participate in an in-depth interview with the navigator. A focus group discussion (FGD) was held with providers six months after PN implementation. Interviews and FGD were conducted in Kinyarwanda, transcribed and translated to English. Descriptive statistics and the framework method were used to analyze survey and qualitative data, respectively.

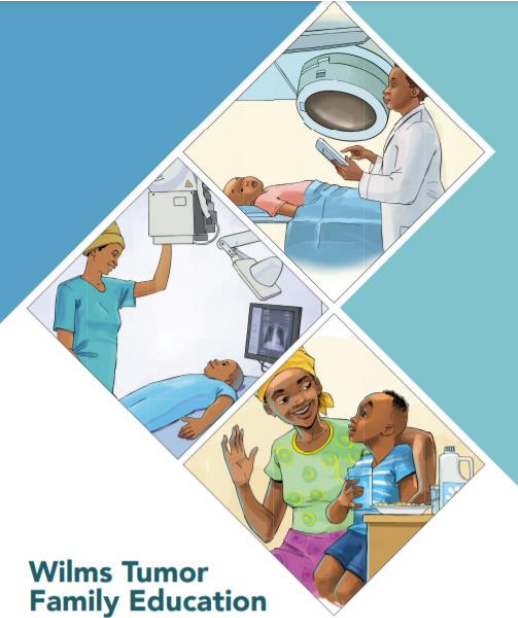


Figure 1: Nephroblastoma education booklet

RESULTS

At the time of analysis, five patients enrolled in PN had completed treatment. All five caregivers were surveyed and three were interviewed. Five providers participated in the FGD (Table 1).

Caregivers found PN and the education booklet helpful in understanding their child's diagnosis, treatment plan and schedule, and treatment side effects.

The book has been useful to us because it contains pictures which show how cancer patients should behave and how people who accompany them should do their duty. In fact, we have learned a lot from it. The book contains everything regarding cancer treatment from the beginning to the end. You can find anything you need from the book. (Caregiver, M)

Since each modality of nephroblastoma treatment is offered at different health facilities in Rwanda, caregivers also appreciated PN in facilitating care referrals and linking them to supportive services.

You [the patient navigator] were always ready to help me whenever I needed assistance. For example, you assisted me when I was taking my child to Kigali for radiotherapy and you helped me find accommodation. When I was at [another hospital for surgery] you helped me get [the surgical pathology] results. That was very helpful because if I had gone myself, I would have paid not less than 30,000 RWF [~30 USD]. (Caregiver, M)

Table 1: Study participant characteristics

Survey participants (n=5)	N	%
Gender		
Female	3	60%
Male	2	40%
Residence		
Eastern Province	1	20%
Western Province	3	60%
Outside Rwanda	1	20%
Age (years, median, range)	32	27-49
Focus group participants (n=5)	N	%
Gender		
Female	3	60%
Male	2	40%
Role at BCCOE		
Physician	2	40%
Nurse	2	40%
Other provider	1	20%

Regular appointment reminders from the navigator often served as a source of motivation for the caregivers to continue treatment for their child, despite numerous challenges faced.

When you have to take your child to the hospital and you have not found the money needed, you are discouraged and you even feel guilty for not being able to provide for your child. You may even suffer from depression as a result of not being able to fulfil your duties as a parent. A message [from the navigator] helps me because, once I have received it, it is like telling me that I must go to the hospital at all cost. (Caregiver, M)

When you call me, I feel pleased and happy. I feel I am an important person for being called by people like you! When you call us, you support us morally. (Caregiver, F)

Providers noted increased adherence to treatment appointments, better care coordination, more timely care transitions and improved advocacy for social support for nephroblastoma patients since PN implementation at BCCOE.

The patient navigator monitors everything. They are always in contact with people involved in the treatment of the patient, be it in [Kigali] or here at Butaro Hospital, the social service department, everywhere. [PN has made] the treatment process go smoothly. (Provider, M)

Caregivers and providers suggested PN be expanded to other diagnoses.

DISCUSSION

Early data from end-users (patient caregivers and healthcare providers) of our new pediatric PN program demonstrated high acceptability. After six months of implementation, clinicians observed specific treatment process challenges that were resolved with PN. Caregivers appreciated relationship with and constant contact from the patient navigator, which provided continuous logistical and emotional support.

We plan to pilot this pediatric program for one year. Next steps will include analyses to evaluate the impact of PN on patient outcomes and expansion of the program to other pediatric diagnoses.

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